

Questions and Answers about Bowel Management

The staff of the Colorectal Center at Cincinnati Children's Hospital Medical Center provides answers to the following questions:

What is Bowel Management and how can I get my son involved in such a program?

We have a dedicated week of [bowel management](#) each month in which members of our clinical team devote their time in structuring a bowel management program specific to your son's needs. The week begins with some radiological tests specific for your child diagnosis prior to the start of the week of bowel management. The results of the tests are then ready for the clinic visit with Alberto Peña, MD or Dr Marc Levitt. Based on the tests and your child's history, a bowel management program is developed.

The bowel management week begins on a Friday and ends the following Friday. The bowel management program will be taught to the family and child if indicated by one of the nurses after meeting with the physicians. This may include an enema regime of an isotonic solution (salt water mixture) or fleets enema. This program will teach you "tricks of the trade" to administer an enema in order to achieve optimal results. A nurse will be available to you each day of bowel management to support you with any questions you may have. Starting on Monday and each day after will consist of obtaining an abdominal X-ray to determine how empty the colon is of stool.

After your child's X-ray is done, you may meet with the nurse to discuss any issues you may have. The X-ray results will be reviewed with the nurses and physicians each day and adjustments may or may not be indicated. It is not necessary for you and your child to see one of the physicians each day.

The last day of bowel management week will consist of one final x-ray and a final visit with Dr. Peña or Dr. Levitt. Their years of experience, and dedication to the bowel management of their patients, have resulted in a 95% success rate.

Why do you feel that a bowel management program is the right choice medically for these children?

We feel that the other alternatives are not as good as the bowel management in terms of quality of life. Of course, the final answer should come from the patient and not from us. We just present the alternatives and the patient and parents are the ones who must decide.

What are the long term effects of daily enemas and medications?

The bowel management program has been implemented for only the last ten years. We have not seen any medical secondary effects that we could attribute to the use of enemas or colonic irrigations. However, we do not know what the consequence could be 20 to 30 years from now. It is important to remember that there are several kinds of enemas that can be administered. A Fleet enema is a phosphate enema and can be toxic when given in excess.

Following the specific recommendations of the manufacturer, we have not seen problems or phosphorus intoxication nor hypoglycemia (low calcium). Many of our patients, on the other hand, receive colonic irrigations or enemas with saline solution which isn't different from the liquid that integrates throughout our body in terms of the concentration of electrolytes. We do not expect or foresee, therefore, any secondary effects from the use of these enemas.

Many of our patients frequently express a common misconception. They think that giving enemas may interfere with nutrition and absorption of nutrients. It is very important for the parents and families to remember that when giving enemas we are only washing the colon and the colon only has stool in it, which is waste. The main absorption of nutrients occurs in the small bowel and our enemas do not wash that part of the intestine. We are really only washing out the waste.

Regarding the use of medications, we only use Immodium in a specific group of patients who have a tendency to suffer from diarrhea. Those patients are the ones who had the old type of procedure for the treatment of imperforate anus: during those operations the surgeons frequently resected part of the rectosigmoid. The consequence is that the patient has a tendency to suffer from diarrhea and we have to slow down the motion of the colon with Immodium to keep the patient clean in between enemas. Fortunately, the operation that we use now emphasizes the need to preserve every single piece of the colon and the rectum, and therefore, we are seeing these types of patients less frequently. Most of our patients do not need any type of medication if

they were operated on with modern techniques. We are unaware of secondary effects attributable to the use of Immodium on a long-term basis.

Why is it so important to start a bowel management program at the age of 2-1/2, when so many "normal" children are still in diapers until almost four years old? Is it a matter of it taking a longer period to achieve success, or are there medical / psychological benefits to starting early?

We believe (and again our bias is shown here) that a child who suffers from fecal incontinence is basically a happy child during the first part of his life when he is still in diapers because, as you mention, he is not different from other children. The problems with these children begin when they have to separate from their protective figures (parents) and start to socialize by themselves in an environment where all their classmates are already wearing normal underwear, whereas the patient is still in diapers. That is the moment when the real problems (discrimination and ostracizing) start, potentially having very serious deleterious psychological effects.

We do not believe that the bowel management program must necessarily start when the child is two and a half years old, but rather the parents should decide when to start. We only emphasize that our patients must wear normal underwear when socializing with other children of the same age who are wearing normal underwear. We have seen patients who have come to us after ten years of attending school in diapers and we believe this is very bad psychologically for the child. The answer is, therefore, that we do not have a specific age to start bowel management. The bowel management must start when the patient is going to be exposed to a social environment where their peers are toilet trained.

Some parents wrote that their doctors tell them that given the chance, the child will eventually achieve bowel control on his / her own, and that no program should be instituted in the meantime. Is this another theory on the management of these children, or is it simply a case by case determination? Do you agree with this in respect to specific cases where the anatomy suggests future control, and is this a possibility for most / some / few children?

There are patients with a bad prognosis, such as those born with a recto-bladderneck fistula. In our statistics, we found that only 15 percent of them developed voluntary bowel movements by the

age of three. We believe that it represents a great advantage in the decision making process for the parents of a child with imperforate anus to have a realistic bowel function prognosis. We consider it tragic how these patients have been handled in the past. Namely, there are children who are born with an anorectal malformation having a bad prognosis, and the parents are not informed of this prognosis and, therefore, have many false expectations.

The surgeons performed the "correct" operation but did not discuss the prognosis with the family. The parents then expect their child to become toilet trained. In the meantime, they start a routine of going from doctor to doctor to gastroenterologist, to dieticians, to psychologists, to psychiatrists and back to the surgeon asking why their child is fecally incontinent. This continues for years. These years are full of suffering and frustration and they also represent a waste of time and money. If the child has a bad prognosis to begin with, our philosophy is to face the reality and protect the child from being exposed to a social setting with dirty underwear.

On the other hand, there are malformations with a better prognosis. For instance, a patient with a rectoprostatic-urethral fistula has a 60 percent chance of developing voluntary bowel movements by the age of three. Our philosophy for this type of case, where the child is not yet toilet trained is different. If the child is about to begin school, we suggest that parents use bowel management for the course of the school year. During their summer vacations, however, we stop bowel management and try to toilet train the child. Three years of age was chosen based on our experience; of course, there are patients who are not toilet trained by this age and become trained one to two years later.

Do daily enemas starting at an early age diminish the chance for the child to achieve control, by not allowing the child to "feel" the internal sensations associated with bowel motility or is this also a case by case determination?

We are unaware of any evidence that the bowel management could interfere with this process. A patient born with a rectourethral-bulbar fistula has an 83 percent chance of becoming toilet trained, and if he is not trained by the age of three, giving him bowel management for one year should not decrease his chances of being toilet trained. We are still looking for answers as to why some patients with the same defect, operated on using the same technique, develop bowel control and others do not.

If we are asked, "Are we sure that the bowel management will not interfere with the potential for the patient to become toilet trained?" the answer is that we cannot be sure of anything because we do not have conclusive scientific evidence of it. The question can also be asked in a reverse manner, which would be, "Are you sure that leaving the child to struggle with dirty diapers, feeling shame in public, will improve their chances of becoming toilet trained?" the answer, again, is that we do not know. If it is valid to express our beliefs, I believe that there is a better chance to toilet train a child who is used to being absolutely clean and odorless for all of his life, than a child who soils all the time.

Among the problems that we have seen is that patients become accustomed to the smell of stool, and do not perceive that their odor upsets the entire family and anyone around them. We have seen terrible psychological problems derived from the fact that parents refuse to provide bowel management with the hope that the child becomes toilet trained and in the meantime, the child goes several years dirty, smelly and segregated. Again, however, we always respect the patient's decision. I truly believe that this is a quality of life issue.

As children get older, do they have a greater chance of learning to "feel," or are daily enemas and medication a life-long necessity?

Yes, there is a higher chance of a child becoming toilet trained as time goes by. Some patients have a borderline type of bowel control. In other words, they have a minimal sensation to perceive when the stool is moving in their rectum. If they are very young and they are busy playing, they do not pay attention to that minimal sensation. As the child grows, he becomes more interested in his own bowel function and he may concentrate on perceiving that weak sensation which could be the difference between bowel control and no bowel control.

At what point is a permanent colostomy the right choice? Many parents wonder if a permanent colostomy is an easier / better choice for the care of these children. What

about psychologically? How do daily enemas and the constant threat of an accident affect self esteem?

In our experience, the decision to have a permanent colostomy is usually taken by an adolescent patient who is tired of being subjected to bowel management. He is now ready to go to college and feels that having a stoma is a better choice than doing bowel management. This group of patients actually represents a very small portion of our total group (five percent). There is no specific time when a permanent colostomy should be opened. It must be the patient's decision. Small children, however, usually accept whatever their parents decide. At some point, the patient starts questioning the bowel management, and expresses dissatisfaction. At that particular time, we find that they are mature enough to discuss the other alternatives and then it is up to them to decide what to do.

Regarding the psychological effects of either daily enemas, constantly feeling dirty, or having a stoma, there is no specific answer. We are dealing with something very subjective. Some of our older patients who are adolescents or adults have great personalities and self esteem, and bowel management does not represent a problem for them. Not only can they cope with this, but they are real leaders and they help us a lot in implementing the bowel management with our other patients. On the other hand, some patients hate the bowel management and prefer a colostomy. Again, this represents only 5% of the entire group. Very few patients prefer to be dirty and in diapers for all of their lives. We have only seen this once or twice and they are usually emotionally disturbed individuals. In summary, the psychological effects depend on the emotional and mental characteristics of each individual.

My child has an imperforate anus and was operated on when he was 6 months old. He is now 4 years old and still in diapers because he constantly passing stool. Does my child need Bowel Management?

The answer is yes. Your child probably suffers from overflow pseudo incontinence. We recommend that all children near toilet training years with an anorectal malformation that suffer from fecal incontinence begin a bowel management program to get them into normal underwear and ready for school without the fear of having accidents.

What is a "laxative trial"?

A laxative trial is offered to patients that have achieved successful bowel management with enemas or that is potty trained. Laxatives are stimulates called "senna" and will stimulate the colon to pass stool. The laxative trials are difficult to achieve success particularly with children that have undetermined sensation and poor muscle control. Some children and families are interested in trailing laxatives during our bowel management week. Dr Pena and Dr Levitt will instruct you as to if your child would be a successful candidate for a laxative trial. The success of a laxative trial and continued success of managing constipation long term is dependent on having a colon clean of stool. Administering laxatives to a patient with anorectal malformation will give your child cramps and episodes of constant stooling or fecal incontinence.

What if my son has problems with the bowel management program after we leave Cincinnati?

Dr. Pena and Dr. Levitt have dedicated themselves to your child's bowel management for as long as he will need bowel management and in most cases it is a lifetime commitment. The members of the nursing staff will ensure you have the ability to reach a member of our clinical staff. We will instruct you to obtain an abdominal x –ray from your local hospital and send it to us to view. Based on the results of the x-ray, we will modify your child's bowel management. Recommendations without an x-ray will be difficult.

Will my child really need bowel management for his entire life?

In most cases, yes is the answer. Children with anorectal malformations suffer from constipation and slow colon motility. Once a child achieves fecal continence, they are happy and dedicated to the program.

Contact the Colorectal Center

For more information or to request an appointment for the Colorectal Center at Cincinnati Children's Hospital Medical Center, please [contact us](#).